



**Manchester
Metropolitan
University**

Galvani, Sarah ORCID logoORCID: <https://orcid.org/0000-0003-3794-9378>
and Wright, Samantha ORCID logoORCID: <https://orcid.org/0000-0003-2045-8433> (2019) Palliative and End of Life Care for People with Alcohol and Drug Problems. In: Policy Standards: A Working Document. Documentation. Metropolis, Manchester Metropolitan University.

Downloaded from: <https://e-space.mmu.ac.uk/623171/>

Version: Published Version

Publisher: Metropolis, Manchester Metropolitan University

Please cite the published version

<https://e-space.mmu.ac.uk>

Policy standards: a working document



Palliative and End of Life Care

for People with Alcohol
and Drug Problems

May 2019 (1st edition)

Professor Sarah Galvani
Dr Sam Wright



Acknowledgements

We are very grateful to all our participants for their time and for their open reflections on their policy and practice experiences relating to palliative and end of life care for people with problematic substance use.

We are grateful to The National Lottery Community Fund (formerly Big Lottery Fund) for supporting the research underpinning these policy standards. We are also grateful to the Chancellor of Manchester Metropolitan University, for funding the Fellowship that enabled us to develop these policy standards. We are particularly grateful to our colleagues in Metropolis, the University's research-led think tank.

We would like to thank Dr Yasir Abbasi and colleagues at Mersey Care NHS Foundation Trust for supporting this work, also Dr Laura Chapman and Dr Sarah Fradsham, Marie Curie Hospice, Woolton, Dr Joanna Roberts, Woodlands Hospice, Liverpool and Nicola Bowtell, and Steve Taylor, from Public Health England for their advice and support.



Care and support
through terminal illness



Mersey Care
NHS Foundation Trust

Community and Mental Health Services



Contents

Terminology	4
The Case for Change	6
Key policy standards	8
About the policy standards	9
Who do we mean by people with experience?	10
1. Develop policy which assertively counters stigma and stereotyping relating to substance use and serious ill health	12
2. Develop national, local and organisational policy that supports co-existing substance use and palliative and end of life care needs in practice	14
Figure 2a. Stages of national policy development	16
Figure 2b. Stages of local policy development	17
Figure 2c. Stages of organisational policy development	17
3. Create policy that promotes accessible care environments and offers the required support to people with problematic substance use at the end of life	19
4. Ensure policy directives bring people together to work jointly across substance use, palliative, end of life and primary care	21
5. Ensure that policies informing health and care education and training equip professionals to work with people who use substances and need palliative or end of life care	23
6. Ensure policy identifies and responds to the needs of people who are important to the person with substance problems at the end of life	25
Overcoming barriers to effective policy development and implementation	28
What should happen next	29
References	31
Appendix A – Resources	32
Policy links	32
Practice resources	34

Terminology

- **COPD** – Chronic Obstructive Pulmonary Disease (for example: emphysema or chronic bronchitis). Typically, a chronic, irreversible airway obstruction resulting in breathing difficulties.
- **End of Life (EoL)** – Refers to the last 12 months of a person's life (as far as that time period can be known).
- **Family** – Refers to family members, close friends and carers – recognising that people with substance use difficulties often have fractured family relationships and may consider close friends to be more of a family to them than their blood relatives.
- **Palliative Care (PC)** – A holistic approach to maximising quality of life for people with terminal or complex illness where symptoms need to be controlled. Focusing on the prevention and alleviation of suffering, this includes not only pain management but also psychosocial and spiritual support for both the individual and their family, friends and carers.
- **Problematic substance use (PSU)** – A subjective definition which differentiates problematic alcohol or other drug use from recreational consumption or non-problematic use. Other terms such as misuse or abuse are often catch all phrases for any illicit substance use rather than focussing as we do here on problematic substance use. Problems may relate to physical or mental health issues, criminal justice involvement, financial and employment difficulties, family life, social support or housing, but may also include feelings of guilt or shame; secrecy about use; concerned family or friends; reliance on alcohol/drugs to relax or feel better; memory loss; or regularly using more than intended.
- **Substance Use (SU)** – refers to the use of alcohol or illicit drugs (including those controlled under the Misuse of Drugs Act 1971). For our research, we are focusing not only on drugs controlled under the Misuse of Drugs Act 1971, but also use of new psychoactive substances (NPS) and misuse of prescription medicines. Use of tobacco is excluded.



The Case for Change

“...it seems completely alien to us why somebody would drink themselves to death but when you understand the context of somebody’s life and the things they’ve been through, it makes sense...”

Substance use professional

This policy document is designed to create greater understanding for a group of people who are as entitled as any citizen to sympathetic and expert care, particularly when they are dying. It is designed to help all those people of good will in the NHS, social and other health care services, who want to answer the call of every patient who is in need.

People with problematic substance use often present with multiple and complex health and social care needs. At one extreme, this is exemplified by the homeless person with a long history of substance use, estranged from their family and suspicious of service involvement and intervention. At the other is the professional whose problematic substance use is better hidden among the protections that their increased wealth and social status affords, yet whose substance use is having an impact on their health and social relationships. In this mix, are strained relationships with family, including children, friends and carers; a group of people who very often need support in their own right. Where this set of circumstances intersects with life-limiting

or terminal illness, the challenges of providing care to all who need it are magnified.

Growing ‘invisible’ need and inequality of care

There are currently no clear estimates of the number of people with problematic substance use in need of palliative or end of life care (Webb et al., 2018). The data are not collected to allow for accurate estimates of incidence or prevalence. However, reports from professionals within hospice services suggest they are seeing increasing numbers of people with problematic substance use at, or near, the end of their lives (Galvani et al. 2018). While such reports suggest an increase in women and younger adults presenting with palliative/chronic healthcare and substance use problems, it is an older cohort of people who are more likely to present with both sets of needs.

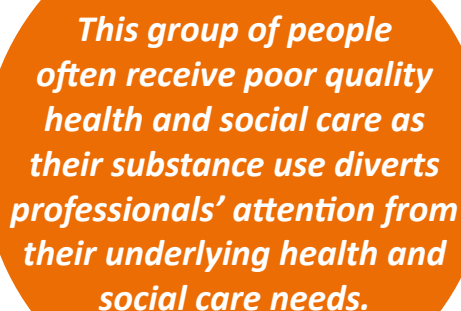


The reported increase in people presenting to palliative and end of life care services with problematic substance use looks set to continue, bringing a range of challenges.

In the UK, it is older generations of substance users who have the highest rates of substance-related hospital admissions, particularly alcohol (NHS, 2018). Trends suggest this will continue as a result of our ageing demographic and our ability to live longer with a range of health problems. Thus, the reported increase in people presenting to palliative and end of life care services with problematic substance use looks set to continue bringing with it a range of challenges and service demands that need to be addressed.

Inequalities in palliative and end of life care have been recognised among many groups of people, including people with conditions other than cancer, people with dementia, people from black and minority ethnic groups, people with mental ill health, learning disabilities or homeless people, to name a few (Care Quality Commission, 2016). People with problematic substance use are not among them. Research suggests this is a group of people who often receive poor quality health and social care, as their substance use diverts professionals' attention from their underlying health and social care needs (Galvani et al, 2018; Templeton et al. 2018; Witham et al. 2018).

This work would focus on the broad range of complex needs including, for example, COPD, Hepatitis B and C, HIV, liver disease, social isolation, mental health difficulties, homelessness, suicide prevention, and cardiovascular diseases. Ideally this work would take place within a public health policy framework – with Public Health England (PHE), Department of Health and Social Care, and NHS England, working together to jointly address these cross-cutting challenges. Only by taking such an epidemiological perspective can we fully gauge the true impact of these complex care needs upon the health and social care system. This document aims to support that conversation, support policy development and facilitate the translation of such policy moves into service delivery plans.



This group of people often receive poor quality health and social care as their substance use diverts professionals' attention from their underlying health and social care needs.



There is a need to start an integrated policy conversation to address effectively the multi-faceted problems faced by people with problematic substance use and terminal health problems.

The need for integrated policy development

This is a newly exposed area of concern that is yet to be reflected in policy. There is a need to start an integrated policy conversation at a national, strategic level, to develop a blended approach with commitment and joint planning from all relevant providers. Such policy should drive the integration of work between NHS Trusts, local authorities and third sector organisations to address effectively the multi-faceted problems that people with problematic substance use and terminal health problems face.

Key policy standards

1

Develop public health policy which assertively **counters stigma and stereotyping** relating to substance use and serious ill health.

2

Develop **national, local and organisational policy** that supports co-existing substance use and end of life care needs in practice.

3

Create policy that promotes **accessible care** environments and offers the required support to people with substance problems at the end of life.

4

Ensure policy directives **bring people together** to work jointly across substance use, palliative/end of life and primary care.

5

Ensure policies informing **education and training** equip health and care professionals to work with people who use substances at end of life.

6

Ensure policy identifies and responds to the needs of **people who are important to the person with substance problems** at the end of life.

About the policy standards

These policy standards are grounded in the practice experience of a range of professionals in leadership and policy roles across health, social care, and specialist palliative and end of life care, and substance use services in Liverpool, England. They have been underpinned by an exploratory research programme that sought a range of perspectives on palliative and end of life care for people with problematic substance use (Galvani, 2018). Thus, the resulting standards reflect a combination of the empirical research findings, the existing international evidence base, and the frontline and strategic experiences of this range of professionals.

There has been much discussion about whether or not the standards presented have an order or priority. They are clearly interlinked and overlapping. What appears to be increasingly clear, is that the inequality in access to good palliative and end of life care for this group of people is often a result of stigma and stereotyping. Without addressing this barrier, practice is unlikely to improve, whatever the policy asks.

The standards have been written for a wide audience of policy makers. These include national policy makers such as public health, national charity, social care and National Health Service leads through to local policy makers including clinical commissioning group leads or directors of local authorities. Last, but not least, they target policy makers within service provider organisations, such as medical directors, chief executives, and team leaders. It is often at organisational level that the innovative and creative work is done to address the challenges of daily practice.

We recognise the difficulty of identifying palliative or end of life care needs among a group of people who die of a number of substance-related conditions other than cancers, or whose substance use co-exists alongside their serious health needs. Timescales for planning can be very short and occasionally non-existent, but for others an improved policy framework will support people with problematic substance use to have better quality palliative and end of life care.

The standards are the first of their kind and are intended to begin conversations about policy development and subsequent practice improvement. They have been kept broad enough for interpretation and application at a local level. Some will be more obviously applicable to substance specialists or palliative and end of life care specialists, while others will apply across the spectrum of health and social care policy.

The goal of presenting a combined policy standards document is to enable joint consideration of the implications of policy development in this area. In other words, while one standard may focus more clearly on palliative and end of life care specialists, for example, there will almost certainly be implications of that standard for joint working and support from other specialist areas of practice. Policy developed with a mutual understanding or a range of perspectives is more likely to succeed than policy developed in silos.

Who do we mean by people with experience?

There are a range of contexts within which people use, and have problems with, substances. Some will not be visible or come to the attention of services until late in their substance using careers, for example, due to failing health. Others will face multiple challenges and needs, be familiar with, and excluded from, statutory services and be reliant on voluntary services. People with

problematic substance use can be completely disenfranchised from their families. In such cases, professionals (including volunteers) can play a crucial support role in their lives. The figure below provides just four examples of people at different points in their substance use and the challenges they, and the people in their lives, may face when they are in need palliative or end of life care.

Person with history of problematic use – no current use

May have serious concerns about stigma/discrimination from services and seek to keep history private.

Support network may also have history of substance use and be wary of negative practitioner judgements.

May decline painkillers despite serious pain due to fears of relapse, dependence, or prescription change and withdrawal.

Person with problematic use within a family setting and not in touch with services

May be minimising health difficulties (or substance use may be masking symptoms), and so they, and their family, do not perceive how ill they are.

Strained family relationships. Support network may not know full extent of their substance use and be struggling to know how to respond.

May underestimate the extent of the harm resulting from their problematic substance use.



Person receiving support to address their problematic use

May be struggling to maintain engagement in treatment as their health deteriorates.

Possibility of strained family relationships ('heard it before') and a peer network of substance users.

Need specialist medical SU input to plan care and pain management addressing concerns including over- and under- prescribing pain medication.

Staff likely to need emotional support and regular supervision to support the complex social and medical needs.

Person who is homeless and using substances problematically

Lack of (or problematic) social support.

Housing status/provision will be a key concern and health and social care needs may have to be addressed on an outreach basis.

Need specialist SU input to plan care and pain management due to a range of basic and complex health and social care needs.

Communication between agencies needs to be clear and efficient to avoid the person slipping through the net.

1

Develop policy which assertively **counters stigma and stereotyping** relating to substance use and serious ill health.

Evidence repeatedly illustrates the stereotyping and stigmatising attitudes faced by people with substance problems from a range of health and social care professionals as well as the general public. Research exploring end of life care and

substance use found many distressing examples where such stereotypical assumptions had led to harm (Galvani et al., 2018). **Key Standard 1** sets out the need to counter such attitudes and locate education within a public health framework.



There is a need to move away from models of individual responsibility and blame, to more community and environmental models that acknowledge the histories and vulnerabilities of this group of people – particularly at the end of life. The stigma associated with drug use means that the treatment that people with substance problems seek is often viewed suspiciously by health practitioners who question whether the individual might be ‘drug seeking’ through prescribed medication. This impairs clinical judgement and has been known to lead to people being refused any treatment despite being seriously ill (Galvani et al., 2018).

As a society, we need to develop a lot more understanding about people with substance problems, and about palliative and end of life care, not least to encourage people to identify themselves to health and social care professionals more readily – so that the true scale of need becomes evident. It is only by removing the stigma associated with problematic substance use that we can ensure that people who need help feel able to seek it, confident in the knowledge that appropriate services and informed professionals exist to respond to their needs.

Within many health and social care organisations, there may be a substantial amount of professional concern about whether and how to ask people using services about their drug and alcohol use and about asking about complex health conditions and plans for end of life. Without prior experience or training on how to hold these conversations, many practitioners feel embarrassed or worried about asking. Yet failure to ask about substance use or palliative and end of life care needs merely avoids the problem, resulting in missed opportunities to engage people in appropriate services.

Case studies

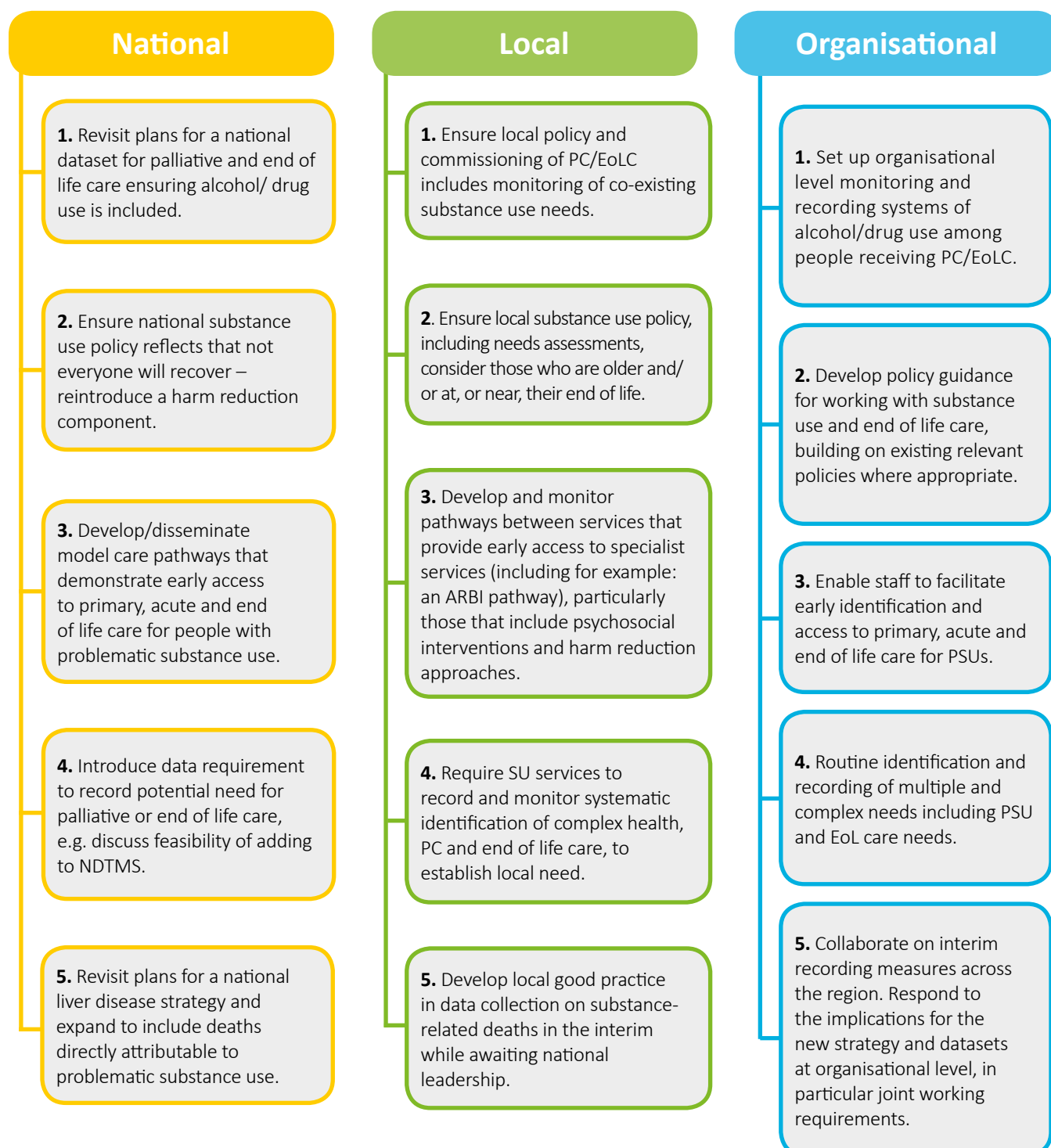
An individual accessing alcohol treatment has been in hospital twice with severe stomach pain. Despite not drinking alcohol recently, the hospital has given him Librium both times – seeking to provide him with a detox rather than finding out about his recent abstinence from alcohol and addressing his actual health concerns (Galvani et al. 2018, p. 39). Good practice would see the health professionals finding out about the current realities of an individual’s life, and not relying on historic medical records and making decisions based on that information.

A medical director of a substance use service was asked to visit a hospice where a woman with cancer was a patient. The woman smoked heroin and was insistent on continuing to do so. The nurses did not know how to manage this and were not receptive to the idea of her leaving the hospice to smoke – yet she could not use illegal drugs on their premises. The medical director was able to alleviate the nurses’ concerns and encouraged them to allow the woman to stay in the hospice whilst leaving the premises for short periods to smoke. This case shows the need to challenge risk management approaches to drug users and accept their need to continue using drugs as one more aspect of holistic, patient-centred care. Good policies should promote palliative and end of life care teams (and other health and social care practitioners) seeking early guidance from substance use specialists to ensure that their approaches are not stigmatising or discriminatory.

2 Develop national, local and organisational policy that supports co-existing substance use and palliative and end of life care needs in practice

There is currently no policy that recognises co-existing substance use and palliative and end of life care needs. **Key Standard 2** commits to improve policy development at national, local and organisational levels. In particular, it strongly supports integrated policy development and commissioning between health and social care

agencies where limited resources could be combined to good effect. These might include partnership working between, for example, public and community-based health services, adults' and children's social care, prisons, probation services, and housing to name a few.



In addition, a number of policy recommendations spanned national, local and organisational levels. These include:

- Appointing a champion or sponsor / organisational lead for taking this work forward.
- Developing appropriate service standards, quality outcomes and measures of success and monitor/evaluate them – including cost effectiveness.
- Committing resources to meet need. For example, accommodation for people with problematic substance use and palliative and end of life care needs who are not able/do not want to stay in a hospice setting but need intensive medical support.

The following Figures 2a – 2c break down the activity into three proposed stages of development: ‘Foundation’, ‘Enhanced’ and ‘Developed’, based on a combination of perceived need, ease of development, and resource demands.

Foundation level: this level is perceived to comprise policy-related activities that are more easily achievable in the immediate to short term. They may, for example, build on existing review or monitoring mechanisms or require smaller changes to existing policy or practice.

Enhanced level: the Enhanced level of policy demonstrates an extra degree of development and attention to supporting people with co-existing problematic substance use and palliative or end of life care needs. This may include initiatives at each level and new collaborations and integrated working, for example.

Developed level: this level may require more time than the others in terms of resources or planning. It would be the level to aim for if seeking to achieve the highest level of excellence in policy standards. It is also the level that includes more creative and aspirational policy responses.

Planning and review tool

The three levels comprise activities that are dynamic and can be adapted to suit individual organisations’ needs. They could be used as a tool for organisational planning and review with additional activities being added as needed. Each level and activity could then be broken down further into more detailed work plans.

Figure 2a. Stages of national policy development

Key standard 2 contains a number of areas for **national** policy attention.



Improving recording and monitoring data

1. *The National Drug Treatment Monitoring System only monitors people in substance use treatment. There are a large number of people who sit outside of treatment who need to be captured and recorded through health and social care monitoring or wider general population survey data.*
2. *Adult Social Care need support to access local NDTMS data to inform their plans for integrated working.*
3. *There also needs to be consideration given to how to access information about people with these co-existing needs within care homes and other residential placements both to determine prevalence and incidence but also to equip staff to respond appropriately through additional training and support.*

Figure 2b. Stages of local policy development

Local policy development is often led by national policy priorities or there is an expectation that national policy will be interpreted and applied at a local level. However, there are opportunities for initiatives to be led by local policy makers in addition to national diktats. As with national level policy, the following three stages are suggested as a combination of perceived need, ease of development, and resource demands.

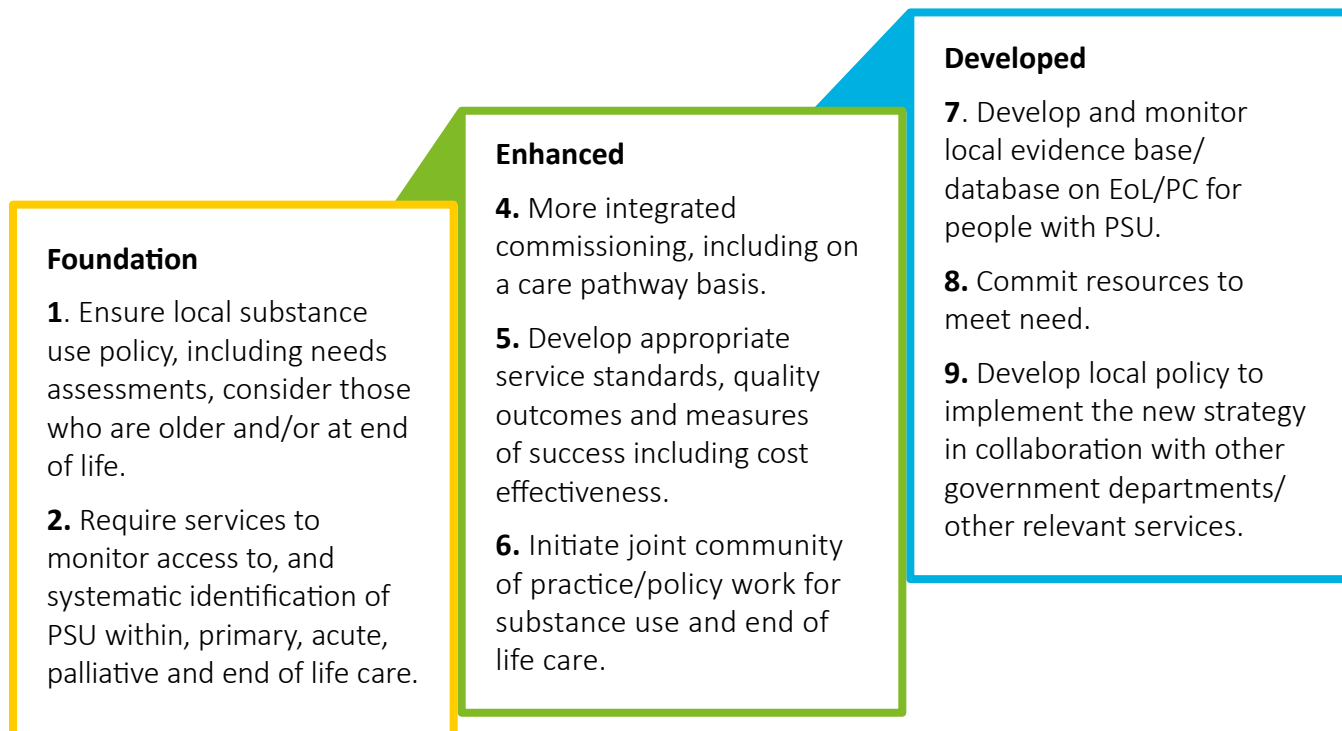
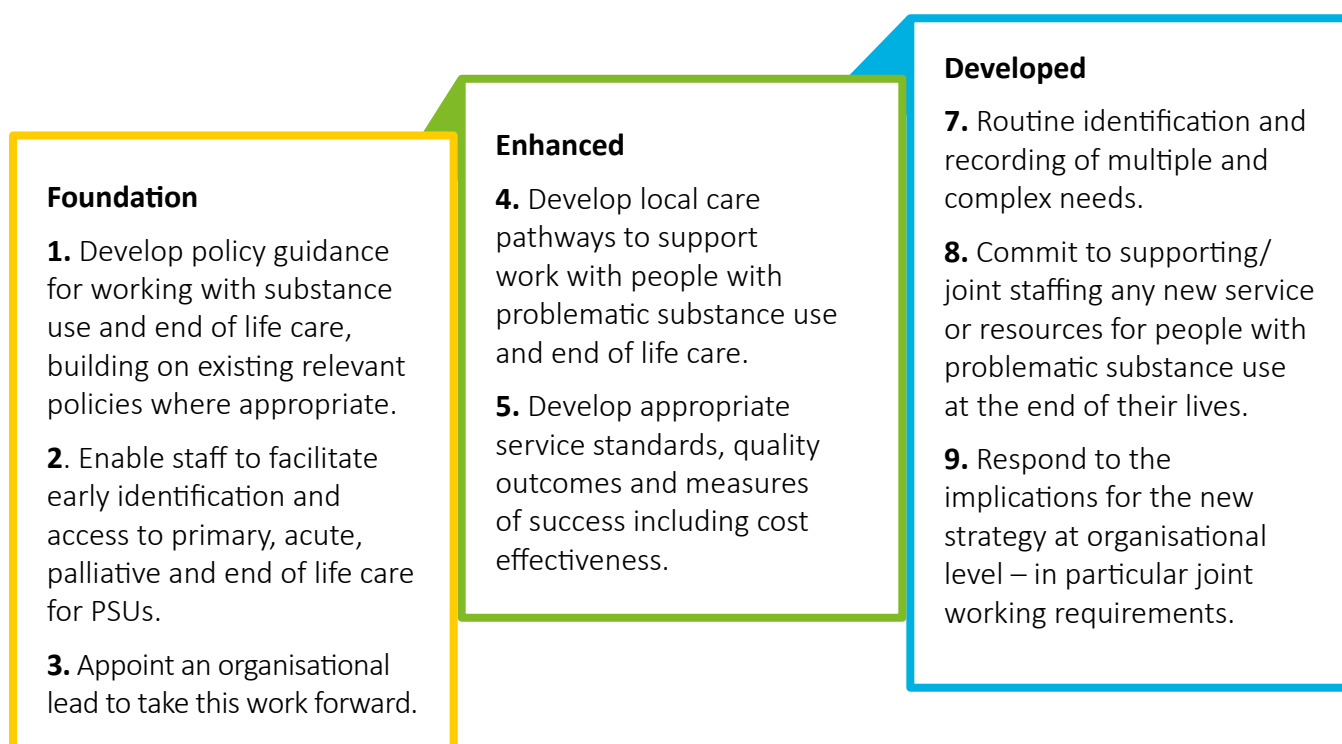


Figure 2c. Stages of organisational policy development

Much good practice in terms of policy development begins at an organisational level where good care or clinical practice develops in response to need. Subsequently, it requires a policy framework to provide consistent application across the organisation. These stages reflect some of the good practice already in place in some organisations and also messages from organisations about what needs to be developed.



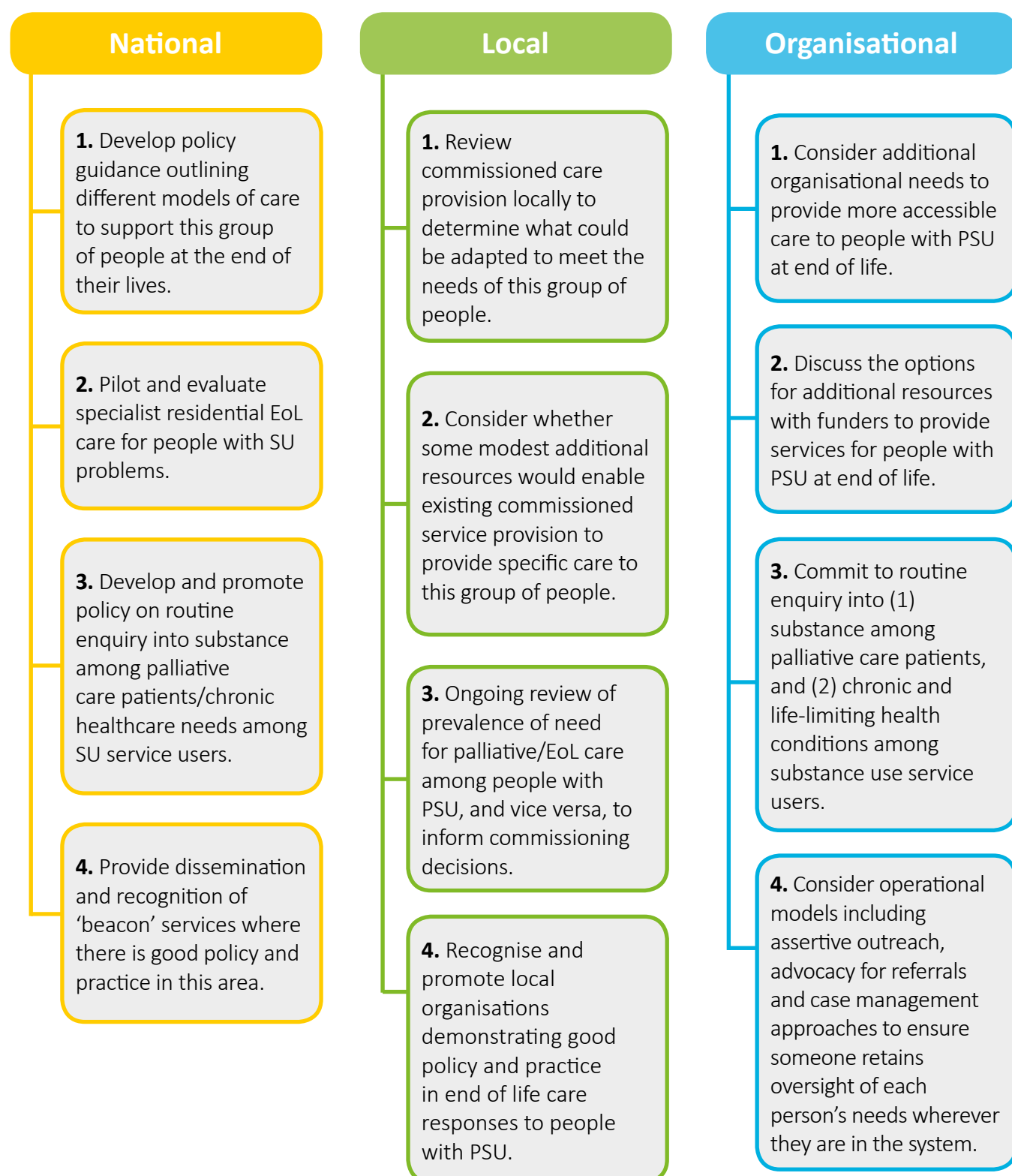
Case study: what good looks like

- **The Liverpool Joint Working Group** arose from work of the Drug-Related Death panel examining sudden deaths among people engaged in substance use treatment. Analysis of these deaths identified a substantial number of people who had died in their 40s and 50s, having had multiple chronic health problems (commonly including COPD), and very complex medication regimens. Many of them had not been accessing any specialist healthcare services. An initial meeting between substance use and palliative care services revealed the latter were equally worried about their staff struggling to manage people, both clinically and psychologically, with problematic substance use and finding elements of the behaviour of some people very challenging. The Liverpool Joint Working Group was set up as a result, inviting local commissioners, healthcare providers, hostels and mental health services to collaborate. The group have identified a lack of clear care pathways and a lack of awareness about each other's services which impairs service delivery. Over the past two years, they have run joint training days between palliative care and substance use service staff to promote awareness of each other's services and foster better working relationships. They also meet on a regular basis to discuss joint areas of concern, thereby building relationships, providing mutual advice, support, knowledge and insight into each other's practice.
- **A specialist older people's alcohol service** based in Birmingham built strong relationships with a Palliative Care Consultant from their local statutory team as well as a Pharmacist in the geographical area. This enabled them to seek advice and support when people in the service presented with potential life limiting conditions (PC consultant) or ask about medication combinations (Pharmacist) taken by people they were supporting.



3 Create policy that promotes **accessible care environments** and offers the required support to people with problematic substance use at the end of life

Appropriate and accessible care environments are required to meet the needs of people with problematic substance use at the end of life. These may take a range of forms and sit within, and outside of, existing service provision. **Key Standard 3** emphasises the need to ensure that such care is available.



Examples of accessible resources needed

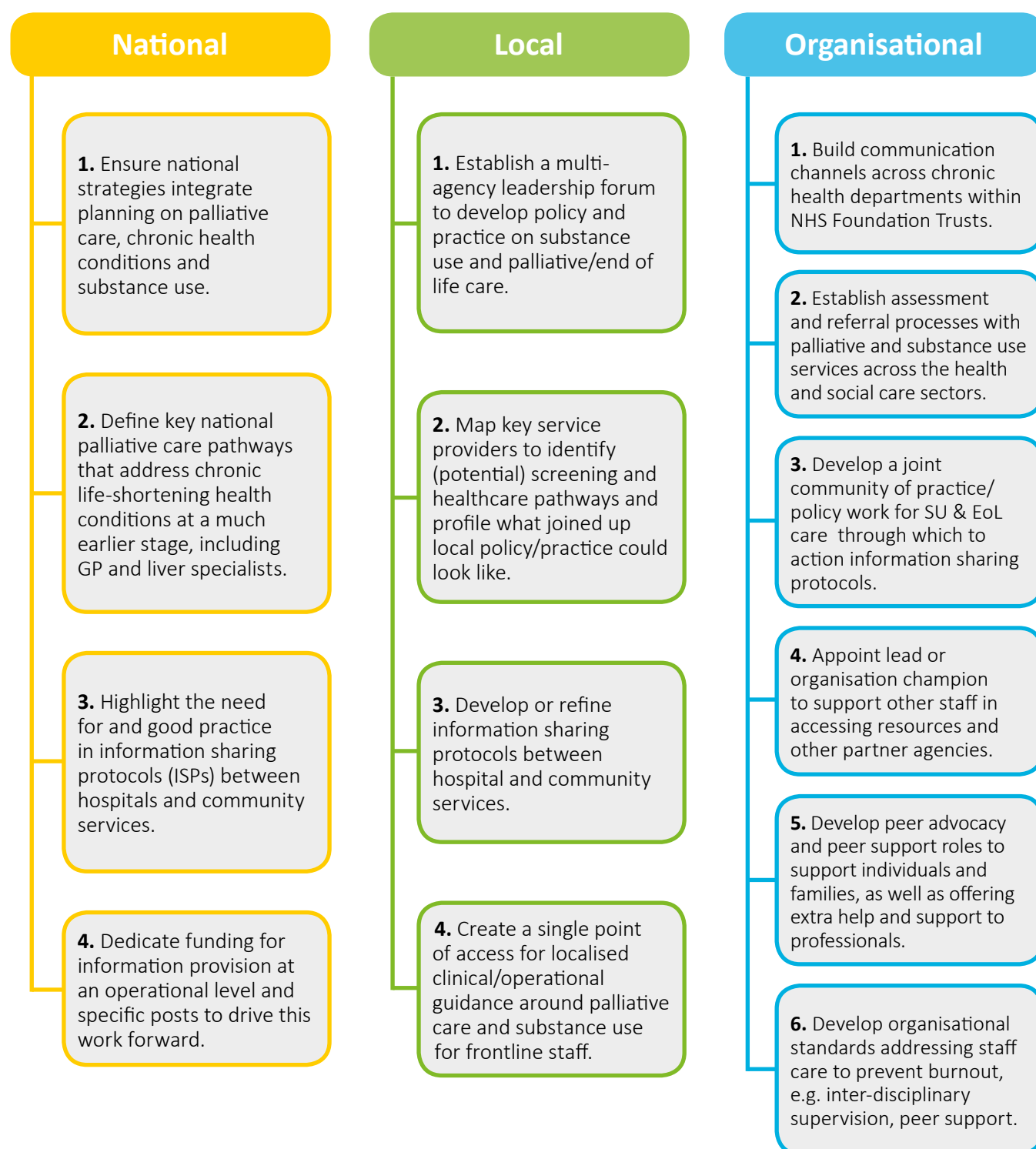
Current gaps in resources include: public-facing navigation help for accessing services; a bespoke service, e.g. residential place for people with EoL care needs who continue to use substances, who need intense care, and are unable/unwilling to live within a hospice environment; complex care beds; complex care packages; 'pathway' specialists to advocate for this group of people (e.g. with acute, primary and social care); single provider subcontracting service provision; and governance structures where accountability is across all agencies.

Case studies: what good looks like

- A strong working partnership was developed between the alcohol service and a hostel for homeless people, one of whose residents was approaching the end of her life and wanted to die there. Working closely together, the hostel, a specialist GP, the local alcohol nurse, homeless nurse, palliative care team and district nurses all collaborated to ensure that the woman died where she wanted. Good policy development would ensure this type of approach on a routine basis for everybody needing palliative and end of life care.
- A woman who was sleeping rough was discovered to have had tests at the local hospital but had self-discharged without knowing what the results were. No attempt had been made by the hospital to contact either her last registered GP or local homelessness services. She had ovarian cancer. Fortunately, she was treated by a GP practice that specialises in supporting people who are homeless and who were very proactive in assessing and dealing with her healthcare needs. A policy to make explicit the need for liaison between hospital services and specialist community services would help to ensure that vulnerable adults are supported irrespective of their self-discharge from inpatient services.
- Systematic screening for hepatitis C was introduced into a specialist substance use service – with automatic referral into Hep C treatment services for anyone with a positive diagnosis. Whilst 36% of patients were identified and then referred, treatment completion was only 12% (which in itself was a successful increase from the previous rate of 5%). However, this highlighted that many people find it hard to move from getting a referral into accessing the service itself – often because of a lack of social support and fear of stigma. In this case, hepatitis C nurses now provide hepatitis treatment in the substance use service – straight after appointments for substitute prescriptions (where needed), in order to maximise attendance. Without this move to enhance the accessibility of treatment, many people with hepatitis C would remain untreated.

4 Ensure policy directives **bring people together to work jointly** across substance use, palliative, end of life and primary care

A clear message from the diverse range of professionals involved in supporting people with problematic substance use at the end of their lives was the lack of consistent joint working and the need for it when working with this group of people. **Key Standard 4** highlights this aspect of policy development and implications for improved practice responses.



Need for joint working policies to support professionals and people with lived experience

General practitioners, acute health care providers and, to a lesser extent, social care providers are most criticised for their lack of understanding, poor or negative attitudes to people with problematic substance use and for not providing good enough care at the end of life (Galvani, 2018). Evidence shows that where effort had been made to develop positive local relationships between Pharmacists, GPs and substance use services, there were notable exceptions. Hospice and substance use staff were viewed as providing good, often holistic, support but there was little joint working (Galvani et al., 2018).

Policies need to recognise the emotional labour inherent in working with these complex issues and allow for effective supervision and support for staff. This will help to maintain the mental health of health and social care practitioners and minimise staff burnout and/or turnover. Staff are likely on occasion to become very upset by what happens. This work is very different to 'traditional palliative care' which is generally calm, controlled and organised.

Case studies: what good looks like

- Robert has respiratory disease and severe breathlessness. As he smokes, the oxygen therapy he needs at home poses risks. Robert's doctor is mindful that he is already on an opiate substitute prescription and wants to share oversight of Robert's opioid treatment with his substance use service. Having maintained Robert well on methadone for a while, both prescribers are now considering trying to switch him to slow-release morphine.
- Gerry has a long history of homelessness, hostel living and substance use. Following his admittance to a hospice, his health improved enough for him to socialise outside the hospice. However, his behaviour became more challenging for the hospice when he was intoxicated and all attempts to talk to him about it failed. As staff needed to consider the tranquillity and well-being of other hospice residents and their families, they had no choice but to evict him. This was an incredibly difficult process for hospice staff as well as resulting in a return to homelessness for Gerry. By being in the hospice, he had lost his place in the hostel. However, a positive solution was found through the staff from the hostel, the hospice and substance use services working together to find a way of keeping him safe by providing care in the community and in the hostel when he was allocated a bed. Such joint working enabled staff to feel less distressed and more comfortable with the necessary course of action. In turn, this can avoid burnout or the avoidance of working with people with complex needs.

5

Ensure that policies informing health and care **education and training** equip professionals to work with people who use substances and need palliative or end of life care

A key requirement for good partnership working and interagency relationships is the need for some mutual understanding of different perspectives, priorities and constraints. **Key Standard 5** focusses on the need for education and training to underpin improved support for people with problematic substance use at the end of life as well as support for staff working with people with complex social and health care needs.



Training and education: examples

There may be a need for training around linking, and sharing responsibility, with social and health care services; people undertaking neuro-triage processes may require greater understanding of the individual's mental and physical capacity.

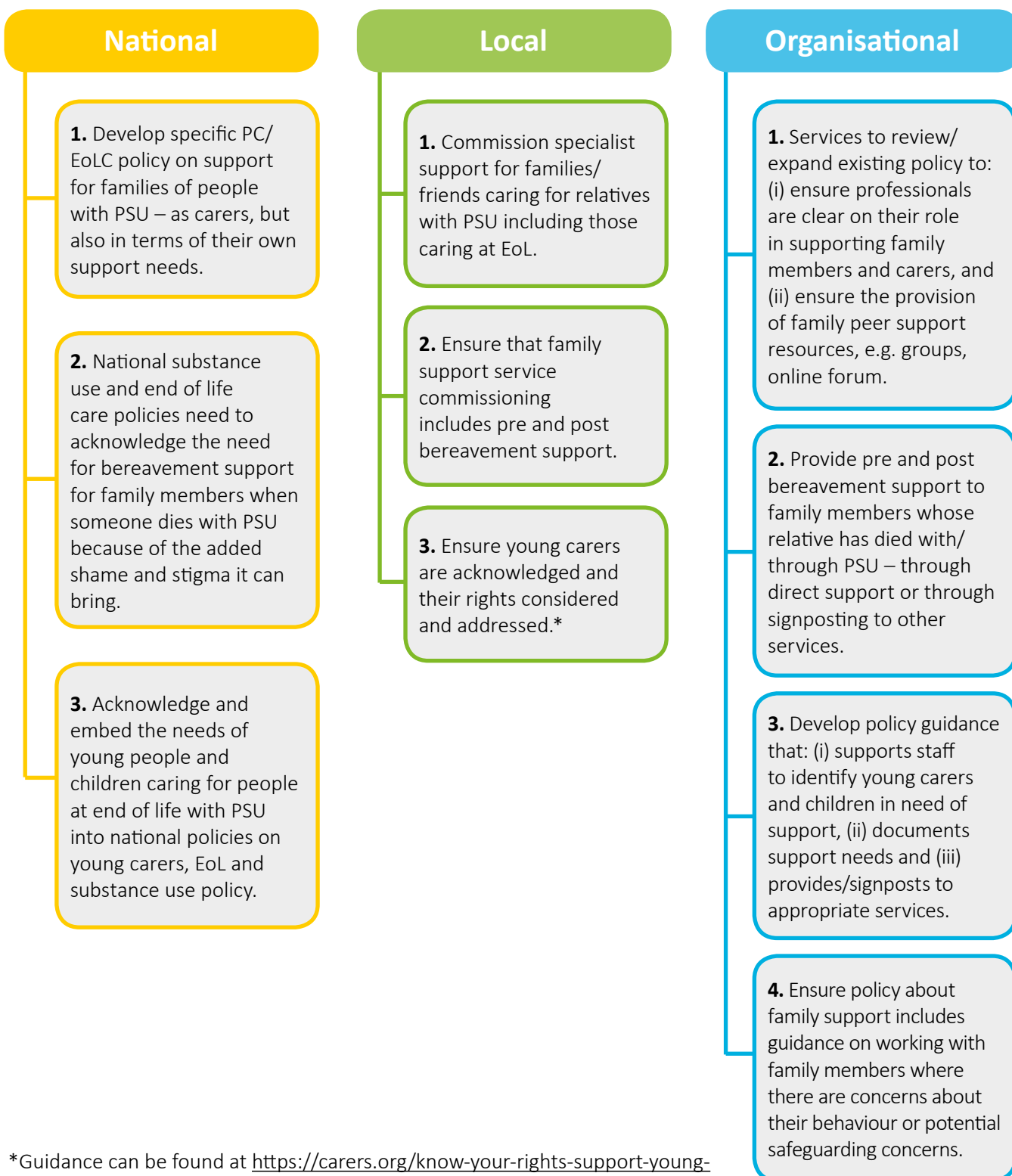
Case studies: what good looks like

- Many hospices accept people's alcohol use without seeking to change it as they approach death, considering that the possible discomfort of abstaining from alcohol may only add to their distress. However, having attended a joint substance use/palliative care training day, one hospice palliative consultant asked a patient who was in the last few weeks of life if they would like to undergo an alcohol withdrawal regimen. They said yes and underwent a very successful detox. This experience was extremely beneficial for him and his family – allowing some meaningful conversations to take place before he died. From a medical point of view, it also made his symptom control more straightforward in the last two weeks of his life. The training had added another tool in the consultant's toolkit of how to support people with problematic substance use at their end of life. Good palliative care policies relating to substance use thus need to tread the fine line between accepting that some people with substance problems will not wish to change their use, while others may welcome the opportunity and should be offered that chance.



6 Ensure policy identifies and responds to the needs of people who are important to the person with substance problems at the end of life

It is well recognised that families, carers, friends play a central role in supporting people who are unwell (NHS, 2019). In the context of palliative and end of life care for people with problematic substance use (PSU), this caring role is vital. **Key Standard 6** focusses on the people who are important to the person with PSU at the end of their lives.



*Guidance can be found at <https://carers.org/know-your-rights-support-young-carers-and-young-adult-carers-england>

In situations where the person dying has a substance problem, the need to support the family – both in terms of their caring role, but also with regard to their own support needs – is even more critical. It is imperative, therefore, that we develop policy and practice that recognises and delivers on support for family carers. The NHS Long Term Plan (NHS, 2019) has begun this conversation. However, appropriately resourced, specialist support needs to be available to families while giving care and after their family member has died. This support should include a focus on identifying and countering any increased vulnerabilities among children in these families (through Adverse Childhood Experiences – ACEs). Longer- term support may well be needed and good policy practice will factor this in to the commissioning process and in the organisational level support on offer.

It is important for policies and practice to recognise that:

- (1) The term ‘family’ needs to be interpreted in the broadest sense – some people have no family or have become estranged from their families. Their closest relationship could be with friends or a worker.
- (2) There may be a need to reconnect people with their estranged families – to let the family know that their relative is approaching end of life; or find and support families when their relative has died.
- (3) Ongoing bereavement support may be required for family, friends or carers – especially if they feel shame or guilt about what happened or consider that they have somehow failed their dead relative.
- (4) People may not want their family told the details of their condition or care. It is important to note that there may need to be transparent yet gentle handling of situations where the family is asking for better communication from staff, but their relative has not given permission to break patient confidentiality.
- (5) The support needs of any children within the family should be of paramount concern, particularly if they have been a young carer and may feel quite traumatised by what has happened. Referrals for support to children’s social care may be needed or to a young carer’s service locally. Safeguarding referrals to social care should be made if there is any indication that children are being maltreated, their health or development is being or may be impaired, and if there are concerns about the child being safe and well cared for. Further information can be found in *Working together to safeguard children* (H. M. Government, 2018).
- (6) Allocated key workers (i.e. substance use and/or homelessness key workers) or a person’s primary clinician may be the most important person in the life of someone with substance problems who has no one else to rely on. This may place a substantial emotional burden on those key workers, especially if a high proportion of their client group faces chronic health problems and premature death. They will need positive and effective supervision and support both in the workplace and easy access/referral to counselling and support outside of the workplace should they require it.
- (7) It is also important to acknowledge that not all family members, friends and carers will offer positive support to their family members, particularly if they have their own problematic substance use or complex needs. This can take up staff time and energy particularly where there are concerns about their involvement with their relative or safeguarding issues. Clear policies for staff are important to minimise the burden, acknowledge the challenges this can pose, and to support them to find a balance between supporting family members and protecting the person at end of life.

Case studies: what good looks like

- A hospice received a complaint from the man's wife because, after five years of abstinence, he was offered, and accepted, alcohol from the hospice drinks trolley. He then bought more on his way home. The hospice was unaware of his history of problematic alcohol use. Unfortunately, he was abusive when drinking, and this return to drinking brought more stress to his wife. Good practice includes the systematic identification of people with (current or past) problematic alcohol or drug use in order to understand how best to support them. Routine enquiry about any current or past problems, allows medical treatment to be carefully attuned to the person's healthcare needs, as well as avoid exacerbating family stress as in the example above. Policies need to recognise the time and resources necessary to properly attend to family dynamics and support everyone in caring for a relative with a substance problem. Without such support for families, informal care may be compromised, resulting in a greater reliance on medical services than would otherwise be necessary.



Overcoming barriers to effective policy development and implementation

There is little point in developing policy without the resources to implement those ideas on the ground. Asking people to get involved in policy work that has no scope to be applied to practice only risks them losing faith in the process and potentially declining involvement in future policy work. It is therefore imperative that policy development is accompanied by a commitment to: (1) adequately resource its implementation, and (2) evaluate and disseminate its impact.

In addition to resource constraints, there are several other barriers to implementing policies in new fields of endeavour that warrant exploration here in order to ensure policy development starts with an awareness of barriers and contingency plans to overcome them.

Possible barrier to PC/EoL-SU policy implementation	Potential method of overcoming barrier
1. Insufficient policy-level understanding of the depth/complexity of need among people with multiple complex needs.	Need to build evidence base on people's complex healthcare needs and how these are compounded for people with substance problems.
2. [The above results in] Inappropriate levels of funding for only short-term/superficial interventions.	Current data collection/outcome measures need refining to enable them to evidence the quality of work required and the positive outcomes that can be attained through the funding of more intensive support.
3. It is currently impossible to measure prevalence given lack of data.	We need to be able to identify the scale of people with substance problems and PC/EoLC needs. NDTMS does not currently record complex health problems. Whilst data on cause of death for people in service (via Drug Related Death reports) could identify chronic health conditions and multiple morbidities, this will not inform us about PC/EoL care needs among existing service users. Nor will it identify the service users who drop out of services because their poor health precludes them from attending.
4. Current Gold Standards Framework definition of/focus on end of life care is unhelpful for people with less predictable trajectories (i.e. organ failure) and so largely excludes people with substance problems.	The GSF needs to be expanded and refined to identify people with life shortening conditions which rapidly move between functioning (feeling well) to decompensating (acutely ill). Use of the Amber Care bundle will help facilitate this (see <i>Practice Resources</i> for a link).
5. End of Life is generally defined by GPs, not all of whom are sympathetic to people with substance problems.	Need to recognise that everyone is in the early stages of learning about the interplay between palliative/ EoL care and substance use and accept that there is little/no clinical guidance as yet. Health and social care professionals need to be confident enough to share their uncertainties; explore each other's thinking processes and priorities in order to reach common understanding; and develop practice themselves.
6. Competition for contracts among different substance use providers inhibits sharing information about good practice.	Need to counter protectionism around services by commissioning partnership practice and rewarding innovative work.

What should happen next

There is an urgent need for policies that reiterate everybody's right to equal access to health and social care. For palliative and end of life care, policies need to include giving people choices about how and where they spend the last months, weeks, and days of their lives.

The London End of Life Clinical Network defines a good death as:

... the best death that can be achieved in the context of the individual's clinical diagnosis and symptoms, as well as the specific social, cultural and spiritual circumstances, taking into consideration patient and carer wishes and professional expertise.

(London End of Life Clinical Network, undated)

There will always be some limitations to the choices that people can be offered due to resource limitations and availability at the time needed. But it is apparent that access to existing palliative and end of life care is particularly limited for people with problematic substance use. Choice is usually not an option for them. Where people are being cared for in the community, it is families, friends and other people important to them, who provide the care. These people comprise a currently unrecognised and underserved population who often need support and care in their own right.

These policy standards begin the conversation about improving support for people with problematic substance use at, or near, the end of their lives. They are not intended to be the final word. They are intended to instigate policy activity at each of the three levels outlined: national, local and organisational. They should be used by organisations in a flexible way, with new activities being added and older ones replaced as the wider policy and practice environment dictates and as we learn more about people's experiences of living, and dying, with problematic substance use.

Partnership in policy and practice

Good policy practice is achievable as the case studies in this document testify. In these early days of policy development, this is an area of mutual learning that is ripe for innovative and timely integrated working. Many of the examples given are practice based, and we hope that national and local policy will capitalise on this frontline knowledge, as well as working to inspire and direct it. As always, the success of innovative policy and practice requires strong leadership at all levels, combined with a willingness to learn from colleagues and people with lived experience.

If you fund, commission or provide palliative care, end of life care or substance use services, we ask that you consider how to identify and respond to this group of people who, as evidence of our ageing demographic suggests, will continue to grow. Better recording and monitoring of people will help to shore up the limited evidence base and assist in planning future services and care. Moreover, greater engagement with people in existing services, and with the people important to them, can only serve to improve our knowledge and understanding.

If you provide primary or acute health care, we ask that you seek to promote good practice and help colleagues to avoid making stereotypical judgements about the reasons for people with PSU, past or present, presenting for health care. People with problematic substance use usually have a range of difficult and traumatic histories and respond well to warmth and empathy. Avoid assuming that their health complaints are only a way to acquire medication, or that basic instructions to “stop using” substances will resolve their ill health. Where appropriate, speak openly and sensitively to people about advance care planning and their wishes at the end of life.

If you provide substance use, palliative care or social care services, commit to learning more and to working together both to improve your practice with the people you support and also to access support and advice in your own right. People living, and dying, with problematic substance use may have complex, multiple needs and there is no need to respond to that on your own. Continue to seek

out support, build relationships and champion good interagency and inter-disciplinary working.

As a person in your own community we ask that you help your families, friends and neighbours to understand more clearly the needs and inequalities faced by this group of people as they approach the end of their lives. This may be by offering individual support, supporting local services, or by challenging stereotypes and stigma when you hear them. Reaching out to family members, friends and carers can also offer a much needed lifeline for people living with stigmatised grief and loss. No one begins life with the intention of developing a problem with alcohol or other drugs and, at the end of their lives, people deserve to die with dignity and respect.



References

Care Quality Commission (2016) *A Different Ending: Addressing inequalities in end of life care*. Available online at: <https://www.cqc.org.uk/publications/themed-work/different-ending-end-life-care-review> [Accessed 4th April 2019]

Galvani, S. (2018) 'End of life care for people with alcohol and other drug problems: what we know and what we need to know. Final Project Report.' Available online at: <http://e-space.mmu.ac.uk/622052/1/EOLC%20Final%20overview%20report%2027%20November%202018%20PRINT%20VERSION.pdf> [Accessed 4th April 2019]

Galvani, S., Dance, C. and Wright, S. (2018) 'End of Life Care for People with Alcohol and other Drug Problems: Professionals' Perspectives.' Final Report. Available online at: <https://endoflifecaresubstanceuse.com/reports-and-resources-2/> [Accessed 25th November 2018]

H.M. Government (2018) *Working Together to Safeguard Children*. Available online at: <https://www.gov.uk/government/publications/working-together-to-safeguard-children--2> [Accessed 3rd April 2019]

London End of Life Clinical Network (undated) 'What is a good death' Available online at: <http://www.londonscn.nhs.uk/publication/what-is-a-good-death/> [Accessed 4th April 2019]

NHS (2018) *Statistics on Alcohol, England*. 2018 Available online at: <https://digital.nhs.uk/data-and-information/publications/statistical/statistics-on-alcohol/2018/part-1> [Accessed 5th April 2019]

NHS (2019) *The NHS Long Term Plan*. Available online at: <https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/> [Accessed 4th April 2019]

Templeton, L., Galvani, S. and Peacock, M. (2018) 'End of Life Care for People with Alcohol and other Drug Problems: Key Informant Interviews.' Final Report. Available online at: <https://endoflifecaresubstanceuse.com/reports-and-resources-2/> [Accessed 25th November 2018]

Webb, L., Wright, S. and Galvani, S. (2018) 'End of Life Care for People with Alcohol and other Drug Problems: Scoping Review of Existing Database Evidence.' Final Report. Available online at: <https://endoflifecaresubstanceuse.com/reports-and-resources-2/> [Accessed 25th November 2018]

Witham, G., Galvani, S. and Peacock, M. (2018) 'End of Life Care for People with Alcohol and other Drug Problems: Rapid Evidence Assessment.' Final Report. Available online at: <https://endoflifecaresubstanceuse.com/reports-and-resources-2/> [Accessed 25th November 2018]

Appendix A – Resources

End of life care for people with problematic substance use

Research *Briefings*, Full Reports, Good Practice Guidance, and other resources from Manchester Metropolitan University's research on end of life care for people with problematic substance use. Available at: <https://endoflifecaresubstanceuse.com/>

To be added to the **Community of Practice** network at ManMet, please contact Dr Sam Wright on sam.wright@mmu.ac.uk

Policy links

Alcohol and Other Drugs

alcoholpolicy.net

Very useful resource with weekly updates on alcohol policy. The link below gives a brief summary of alcohol policy history. At the time of writing, there is a new alcohol strategy planned but no clarity about when it will be published.

<https://www.alcoholpolicy.net/2018/05/new-alcohol-strategy-plans-and-further-minimum-pricing-review.html>

Alcohol and drug treatment and recovery – why invest?

<https://www.gov.uk/government/publications/alcohol-and-drug-prevention-treatment-and-recovery-why-invest/alcohol-and-drug-prevention-treatment-and-recovery-why-invest>

Alcohol Commissioning Support 2019-2020: principles and indicators

<https://www.gov.uk/government/publications/alcohol-drugs-and-tobacco-commissioning-support-pack/alcohol-commissioning-support-pack-2018-to-2019-principles-and-indicators>

Drug Strategy 2017

<https://www.gov.uk/government/publications/drug-strategy-2017>

Drug Misuse Treatment in England: Evidence of Outcomes

<https://www.gov.uk/government/publications/drug-misuse-treatment-in-england-evidence-review-of-outcomes>

EU alcohol strategy

<https://www.parliament.uk/business/committees/committees-a-z/lords-select/eu-home-affairs-sub-committee-f/news/alcohol-strategy-report-publication/>

Local Alcohol Profiles for England

<https://www.slideshare.net/PublicHealthEngland/local-alcohol-profiles-for-england-february-2019>

NICE guidance on alcohol

<https://www.nice.org.uk/guidance/lifestyle-and-wellbeing/alcohol>

NICE guidance on drug misuse

<https://www.nice.org.uk/guidance/health-protection/drug-misuse>

Statistics on Alcohol, England 2019

<https://digital.nhs.uk/data-and-information/publications/statistical/statistics-on-alcohol/2019>

United Kingdom Drug Report 2018

http://www.emcdda.europa.eu/countries/drug-reports/2018/united-kingdom_en

Palliative and End of Life Care

Ambitions for Palliative and End of Life Care

<http://endoflifecareambitions.org.uk/>

Deaths related to drug poisoning in England and Wales. Statistical Bulletins.

<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsrelatedtodrugpoisoninginenglandandwales/previousReleases>

Dying to care: a report into social care at the end of life

https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/december-2016/dying_to_care.pdf

Equity in the provision of palliative and end of life care in the UK

<https://www.mariecurie.org.uk/globalassets/media/documents/policy/marie-curie-reports/state-of-the-nations-mariecurie-report-england.pdf>

Gold Standards Framework

<http://www.goldstandardsframework.org.uk/>

Hospice UK policy priorities

<https://www.hospiceuk.org/policy-advocacy/policy-priorities>

Making Every Adult Matter (MEAM)

<http://meam.org.uk/multiple-needs-and-exclusions/>

Marie Curie's Policy publications archive

<https://www.mariecurie.org.uk/policy/publications>

NICE End of Life Care documents

<https://www.nice.org.uk/guidance/health-and-social-care-delivery/end-of-life-care>

Pallaborative Network

A collaboration of health care professionals working in specialist palliative care, patients and members of the public from across the North West of England, working to improve the quality of care for people with advanced progressive disease and to ensure care is based on the best and most up to date evidence possible. The website contains a range of [clinical audit](#), [guideline development](#) and [education materials](#), useful for all health care professionals who care for people with advanced, progressive disease. The [clinical standards and guidelines](#) for palliative and end of life care are developed using a robust process and are [NICE accredited](#). <https://pallaborative.org.uk/>

Palliative Care and the UK nations, implications for England

<https://www.mariecurie.org.uk/globalassets/media/documents/policy/marie-curie-reports/state-of-the-nations-mariecurie-report-england.pdf>

The GSF Prognostic Indicator Guidance

<https://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf>

Practice resources

Adfam

Adfam is the national organisation working with and for families affected by drugs and alcohol.
<https://www.adfam.org.uk>

Al-Anon Family Groups

This fellowship, based on 12 step models of peer support, offer support to families affected by a relative's problem drinking.
<http://www.al-anonuk.org.uk/>

Amber Care Bundle

A communication and planning tool for clinical teams to proactively manage the care of hospital patients who are facing an uncertain recovery and who are at risk of dying despite treatment.
<https://www.ambercarebundle.org/homepage.aspx> [Accessed 26th March 2019] See also: Guy's and St Thomas' NHS Foundation Trust 2015 *The AMBER care bundle – a guide for patients, their relatives and carers*.
<https://www.ambercarebundle.org/documents/amber-care-bundle-a-guide-for-patients-their-relatives-and-carer.pdf>
[Accessed 26th March 2019]

Cruse

Cruse supports people who have been bereaved due to the death of someone close.
<http://www.cruse.org.uk/>

DrugFAM

DrugFAM provides support to families, friends and carers who are struggling to cope with a loved one's addiction to drugs or alcohol.
<http://www.drugfam.co.uk/>

Dying Matters

Dying Matters aims to help people talk more openly about dying, death and bereavement, and to make plans for the end of life. Among a range of services, it offers *Find Me Help* which is the UK's most comprehensive directory of services for people in the last years of life, their families, carers and friends – <https://www.dyingmatters.org/>
[Accessed 26th March 2019]

IRISS

Evidence summary on palliative and end of life care for people with alcohol-related brain damage.
<https://www.iriss.org.uk/resources/esss-outlines/palliative-care-arbd>

Macmillan Cancer Support

Macmillan provides practical, medical and financial support and end of life care and pushes for better cancer care.
<http://www.macmillan.org.uk/information-and-support/coping/at-the-end-of-life>

National Council for Palliative Care

NCPC is an umbrella charity for organisations in the UK working with people in palliative or end of life care. <https://www.ncpc.org.uk/>
[Accessed 26th March 2019]

The Royal College of Anaesthetists (RCoA)

The UK professional body responsible for the quality of patient care through the maintenance of standards in anaesthesia, critical care and pain medicine – provides a lot of useful information about opioid use and pain management:
<https://www.rcoa.ac.uk/faculty-of-pain-medicine/opioids-aware/opioids-and-addiction/palliative-care>

Rowcroft Hospice

Guidance on prescribing for people with using substances.
<https://www.rowcrofthospice.org.uk/wp-content/uploads/Rowcroft-Hospice-Palliative-Care-Prescribing-For-Substance-Misusers.pdf>

The Serious Illness Conversation Guide

<https://www.ariadnelabs.org/wp-content/uploads/sites/2/2015/08/Serious-Illness-Conversation-Guide-5.22.15.pdf>

The Society for the Study of Addiction (SSA)

<https://www.addiction-ssa.org/factsheets>

The SSA has a range of factsheets available split into categories. The first category includes a factsheet on Palliative Care, the third category includes a factsheet on communication and substance use. However, there are range of factsheets that will likely be of interest.

SMART Recovery Family and Friends Programme

SMART UK offers group-based support to those affected by another's substance use.

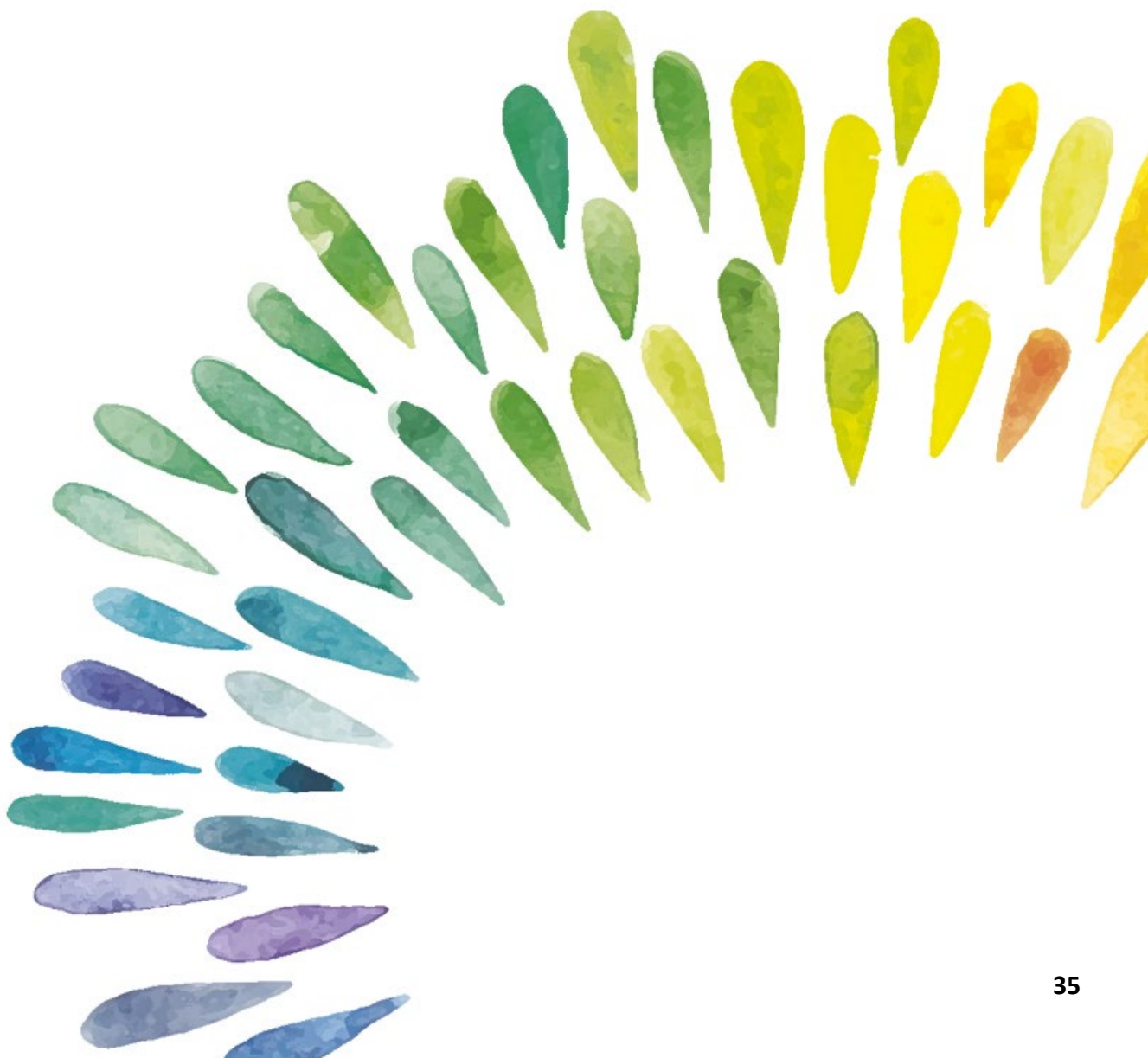
<https://www.smartrecovery.org.uk/family-friends/>

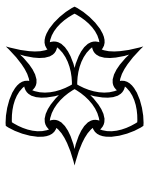
The Supportive and Palliative Indicators Care Tool (SPICT).

Devised by the University of Edinburgh (Updated)

(2018) www.spict.org.uk

[Accessed 26th March 2019]





**Manchester
Metropolitan
University**

